# 5 Impact of upper limb complex regional pain syndrome type I on everyday life measured with a novel upper limb-activity monitor

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## 5.1 Abstract

**Background:** Complex regional pain syndrome type I (CRPSI) often leads to serious activity limitations in everyday life. To date, however, limitations in patients with CRPSI of an upper limb have not been objectively measured. **Aim:** To determine the long-term impact of upper limb CRPSI on general mobility and upper limb usage during everyday life, as measured with a novel upper limb-activity monitor (ULAM). **Method:** In ten female chronic CRPSI patients and ten healthy control subjects, 24-h activity patterns were measured with the ULAM. This ULAM consists of body-fixed acceleration sensors, connected to a recorder worn around the waist. The ULAM automatically detects upper limb activity during mobility-related activities. Several outcome measures related to general mobility and upper limb usage were compared between patients and controls. **Results:** CRPSI in the dominant upper limb had modest impact on general mobility; i.e. on the percentages spent in body positions and body motions and on mean intensity of body activity. For upper limb usage outcome measures during sitting there was a marked difference between CRPSI patients and controls. Especially patients with dominant side involvement clearly showed less activity of their involved limb during sitting, indicated by significant differences for the mean intensity ($p=0.014$), percentage ($p=0.004$) and proportion ($p=0.032$) of upper limb activity. **Conclusion:** These ten chronic CRPSI patients still had limitations in upper limb usage during everyday life 3.7 years (average) after the causative event.

## 5.2 Introduction

Complex Regional Pain Syndrome type I (CRPSI; also known as reflex sympathetic dystrophy or posttraumatic dystrophy) is a complex entity comprising a combination of sensory, trophic, autonomic and motor impairments that usually follows trauma or surgery and is generally expressed in the extremities [1]. Etiology and pathophysiology of this syndrome have been studied, but with conflicting results and theories [2, 3]. Because CRPSI is not yet fully understood and variously defined, it remains a topic of discussion [4-11]. Moreover, a wide variety of treatments and numerous measures to determine treatment outcome have been described [2]. Most outcome measures for CRPSI concentrate on impairments [12], which is remarkable because CRPSI can lead to serious activity limitations in everyday life [5, 13-21]. Activity limitations associated with upper limb CRPSI are directly related to upper limb usage during everyday life (e.g. problems with getting dressed or personal hygiene). In addition, limitations in general mobility may also occur (e.g. hypoactivity). In spite of numerous research reports on CRPSI, there is little information on activity limitations [19, 22, 23]. So far, studies on activity limitations of patients with CRPSI have only used (retrospective) scales and questionnaires: no instruments have been employed that measure what patients *actually do* and whether they *actually use the upper limbs* during everyday physical activities [12]. The importance of such objective outcome measures for CRPSI research has recently been stressed in a consensus report [24].

The Activity Monitor (AM), developed and validated in our department [25-30], is a portable device based on ambulatory accelerometry that can be used for long-term measurement of mobility-related activities (body positions and body motions, including transitions). The AM consists of acceleration sensors attached to thighs and trunk, connected to a small recorder that is worn in a padded bag around the waist. The device allows to automatically detect mobility-related activities (e.g. lying, sitting, standing, walking, cycling and general movement). Measurement of these activities enables assessment of limited general mobility, e.g. lying down or sitting most of the day, or a low number of transitions. To determine activity limitations of subjects with disorders related to upper limbs, such as CRPSI, we extended the possibilities of the AM, resulting in an upper limb-activity monitor (ULAM) [31]. The ULAM enables to determine whether or not the upper limbs are active when a subject is performing one of the mobility-related activities. In a feasibility study [31], subjects performed an activity protocol, representing several forms of real-life upper limb (non-)usage that were described in a framework. Agreement scores between the ULAM output categories and video recordings (reference method) were calculated. The ULAM output categories that were of special interest from a rehabilitation point of view were satisfactorily detected. It was considered feasible to use the ULAM in future studies in patients with an upper limb disorder. The combination of data on mobility-related activities and activity of both upper limbs allows to obtain more specific information than with the more frequently used, less advanced techniques, such as a wrist

activity monitor/actigraph/actometer [32-36]. The ULAM enables detailed measurement of what subjects actually do and can therefore be used to determine the impact of upper limb disorders, such as CRPSI, on everyday life. Such an instrument has never been used before in CRPSI research. Therefore, the aim of this study was to determine the long-term impact of CRPSI in one of the upper limbs on everyday life, as measured with the ULAM.

The research questions were:

- Does CRPSI in one upper limb have an impact on general mobility during everyday life?
- Does CRPSI in one upper limb have an impact on upper limb usage during everyday life?
- Does the impact depend on whether the dominant or non-dominant side is involved?

## 5.3 Methods

*Design and subjects*
Twenty subjects volunteered to participate in this descriptive comparison study: ten female chronic CRPSI patients and ten healthy controls with the same age (± 3 years), gender and family situation. In five patients the dominant side was involved and in the other five the non-dominant side; the right side was dominant in all control subjects. Mean age was 50.2 (sd ± 15.7) years in the patients and 50.3 (sd ± 16.6) years in the controls. Inclusion criteria for CRPSI were 1) presence of the criteria of Veldman [37] at the moment of diagnosis, and 2) presence of CRPSI-related complaints at the moment of measurement. The criteria of Veldman were a) four or five of the following: unexplained diffuse pain, different skin color relative to other side, diffuse edema, different skin temperature relative to other side, limited active range of motion, b) occurrence or increase of signs and symptoms after use, and c) presence of signs and symptoms in an area larger than primary involved, including the area distal to primary injury. These criteria do not substantially differ from the criteria formulated by the International Association for the Study of Pain (IASP) [1, 8]. Table 5.1 presents some patient characteristics, which were measured with the following instruments: a Visual Analogue Scale (VAS), goniometry, hand-held dynamometry, a volumeter (Volumeters Unlimited) and an infrared thermometer (Braun Pro 3000 Type 6014). None of the patients had contractures or dystonia. All the patients reported perceiving activity limitations as a consequence of CRPSI. Written and oral information was given, and informed consent was obtained. The study was approved by the Medical Ethics Committee of Erasmus MC.

*Table 5.1: Characteristics of the ten patients for both subgroups separately.*

| Patient number | Dominant side | Involved side | Age (years) | Duration since onset (months) | Time between onset & diagnosis (months) | Currently treated | Preceding event |
|---|---|---|---|---|---|---|---|
| 1 | left | left | 19 | 34.5 | 2 | Y both | fractures |
| 4 | right | right | 47 | 41 | 18.5 | Y ther | spontaneously |
| 5 | right | right | 56 | 143.5 | 1.5 | Y phar | fracture |
| 7 | left | left | 44 | 10 | 4.5 | Y ther | fracture |
| 9 | left | left | 54 | 33 | 1 | N | spontaneously |
| 2 | right | left | 80 | 39.5 | 0.5 | N | heamorrhage |
| 3 | right | left | 36 | 16.5 | 1 | Y phar | fractures |
| 6 | right | left | 56 | 9.5 | 2.5 | Y ther | dupuytren |
| 8 | right | left | 58 | 30 | 1.5 | N | fracture |
| 10 | right | left | 53 | 89.5 | 0.5 | N | fracture |

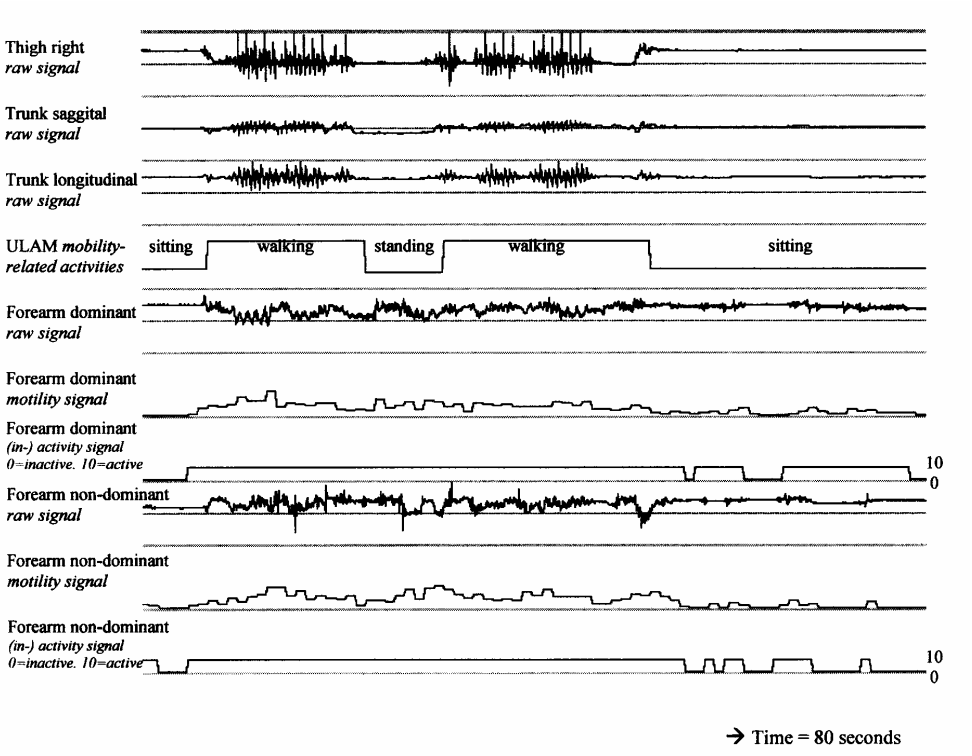
| Patient group | Momentary pain | Pain after strain | Active Range of Motion | Grip strength | Temperature hand | Volume hand | Productivity status |
|---|---|---|---|---|---|---|---|
| dom | + + | + + | + + | + | o | - | Social services |
| dom | + | + + | + + | + + | - | - | Work compensation |
| dom | + | + | + + | + | - - | - | Work compensation |
| dom | + | + + | + + | + + | o | o | Work compensation |
| dom | + | + + | + + | + + | - - | + + | Work compensation |
| nondom | + | + | + | o | - | o | Retired |
| nondom | + | + + | + + | + + | o | + | Work compensation |
| nondom | o | + | + + | + | + + | o | Housewife |
| nondom | + | + | + | o | o | o | Voluntary work |
| nondom | + + | + | + + | + | + | o | Working (parttime) |

*Current treatment is classified as: N = no treatment anymore, Yther = yes; therapeutic treatment either acupuncture, physical, manual or occupational therapy, Yphar = yes; pharmacological treatment, including analgetics and peripheral vasodilators, Yboth = yes; both pharmacological and therapeutic. Presence and severeness momentary pain, pain after strain, Active Range of Motion (AROM) of wrist & the two most impaired fingers, grip strength, temperature of the dorsal aspect and volume of the hand were determined. For AROM, strength, temperature and volume, intra individual comparisons of the involved and non-involved sides determined presence or absence. These signs and symptoms were classified as follows: o = absence, + = mild presence, + + = clear presence. Temperature and volume symptoms were indicated as positive (higher temperature and presence of oedema of the involved side) or negative (lower temperature and presence of tissue atrophy of the involved side).*

*Upper Limb-Activity Monitor*

The technique of ambulatory accelerometry is based on long-term monitoring of signals from body-fixed acceleration sensors. Information on general mobility can be obtained by determining which mobility-related activities (body positions, body motions and transitions between positions) are performed, when, how often, and for how long [30]. Studies using video recordings as a reference method have shown that these mobility-related activities can be validly quantified [26-30] and that differences in everyday physical activities between groups can be detected [38, 39], which supports the validity and usability of such a technique in clinical research.

*Figure 5.1: An example of 80 s of several signals and the automatically detected output of mobility-related activities and upper limb (in-)activity of the dominant and non-dominant forearms of a control subject. ULAM outcome measures are composed of the signals of the mobility-related activities and the forearms signals.*



The ULAM allows to obtain information on upper limb activity of both upper limbs in relation to mobility-related activities [31]. Uni-axial piezoresistive acceleration sensors (Analog Devices, ADXL201) were used (size 1x1x0.5 cm). The raw acceleration signals are expressed in g (9.81 ms $^{-2}$) and are a combination of two components: gravitational acceleration and accelerations due to activity [30, 40]. The magnitude of these components depends on the extent and direction of the accelerations with regard to the sensitive direction. To detect mobility-related activities, one sensor was placed lateral on the right thigh halfway between the spina iliaca anterior superior and upper side of the patella (sensitive direction in sagital plane) and two sensors on the sternum (sensitive direction in sagital and longitudinal plane). To detect upper limb activity, two sensors were attached on each forearm just proximal from the wrist joint (sensitive direction in sagital plane being in the anatomical position). The sensors were attached to Rolian Kushionflex$^{TM}$ or silicon based stickers (Schwamedico) with double-sided tape; both materials can be fixed directly on the skin. The raw acceleration signals were stored digitally on a 40 MB PCMCIA flash card (Sandisk, USA) with a sample frequency of 32 Hertz. After the measurements, the raw data were downloaded onto a PC for analysis.

Detection of mobility-related activities and upper limb activity was done by automatic kinematic analysis based on signal processing and inferencing language (SPIL) routines, yielding 'C'-code [41]. For detection, three feature signals are derived from each raw accelaration signal: the angular, motility and frequency feature, each with a time resolution of 1 s. The subsequent steps of analysis (activity detection and postprocessing) have been described previously [26-28, 30, 38, 39]. Briefly, for each activity and for each feature signal, a maximum and minimum value is pre-set. Each second, the 'distance' from the actual feature signal value to the pre-set range is calculated for each feature signal from each sensor. The mobility-related activity with the lowest total distance is detected. During post-processing, wrongly detected mobility-related activities (e.g. time spent with transport is currently not 100% well-detected) may be edited using SPIL routines to unobtrusively detect the outcome measures of interest.

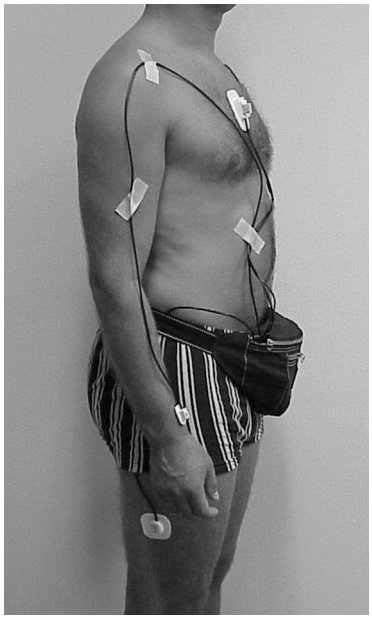
To detect upper limb activity, one of the three features i.e. the motility feature was used. This motility feature is created after zero-phase finite impulse response high pass filtering (0.3-16 Hz) of the raw acceleration signal, rectifying and averaging over 1 second. The value of this signal depends on the variability of the raw signal around the mean and is also expressed in g (9.81 ms$^{-1}$). The variability of the raw upper limb acceleration signal can be regarded as a measure for upper limb activity; the more the value is varied, the higher the motility value, the more the upper limb activity. To determine whether an upper limb was active, it was automatically determined (each second) whether the motility values of an upper limb sensor exceeded a preset threshold assigned to the mobility-related activity that was performed during that second [31]. Each second the motility values exceeded the threshold, the ULAM signal for the upper limb forearm was positive, indicating upper limb activity (figure 5.1).

Each second the motility value did not exceed the threshold, the ULAM signal for the upper limb forearm was zero, indicating upper limb inactivity.

*Protocol*

Subjects were measured during a 24-hour period during one randomly selected weekday (and night). Patient and control were measured within 3 weeks to avoid the possible effect of season. To minimize interference with normal everyday activity patterns, the ULAM was fitted at home (figure 5.2). Subjects were instructed to continue their ordinary everyday physical activities, but were not allowed to swim, take a bath or shower while monitored. To avoid bias, initially the exact technique of the ULAM was not explained. After the measurements, the subjects were visited again to remove the device, to determine several patient characteristics, to make an inquiry about which activities were performed during the last 24 h and about convenience of wearing the ULAM. Furthermore, complete information was given about what the ULAM exactly measures and, of course, the reason for not having given that information before. All subjects agreed with this procedure.

*Figure 5.2: A subject wearing the Upper Limb-Activity Monitor.*



*Outcome measures*

To obtain information about the impact on performing mobility-related activities, the following general mobility outcome measures were used:

- Percentages spent in body positions (lying, sitting, standing) and body motions (walking, cycling, general non-cyclic movement) expressed as percentages of the 24-hour measurement period,
- Number of transitions between body positions,
- Number of walking periods (> 10 seconds),
- Mean intensity of body activity (in g), expressed as the mean value of the motility signals of the trunk and leg sensors. This mean value over the 24-hour period (excluding time spent with transportation, because of external vibrations) can be regarded as a general measure for the intensity of everyday physical activity.

To determine the impact of CRPSI on upper limb activity in relation to mobility-related activities the following upper limb usage outcome measures were used:

- Mean intensity of upper limb activity during sitting and standing, expressed as the mean motility value of an upper limb during the time that a subject was sitting and standing. Upper limb activity during standing and sitting were considered most important, because, in our opinion, limitations in upper limb usage as a consequence of upper limb disorders are mainly expressed in everyday life during these body positions.
- Percentage of upper limb activity of the upper limbs during sitting and standing, expressed as percentage of the time the upper limbs were active (exceeding the motility threshold) while the subjects were sitting and standing,
- Proportion of upper limb activity of one side relative to the other side during sitting and standing, expressed a ratio: the percentage of activity of the non-dominant upper limb relative to the percentage of activity of the dominant upper limb. For subjects with dominant side involvement a ratio higher than the controls indicated more limitations. For subjects with non-dominant side involvement a ratio lower than the controls indicated more limitations. A ratio of exactly one meant equal activity of both upper limbs.

To determine whether the impact depends on dominant or non-dominant side involvement, the outcome measures described above were also analyzed for both patient subgroups compared to their controls. In the results section, the total group of CRPSI patients will be referred to as "$Pnt_{tot}$" and the total group of control subjects will be referred to as "$Crl_{tot}$". Patients with the dominant side involved will be designated the "$Pnt_{dom}$" group and patients with the non-dominant side involved will be designated the "$Pnt_{non\text{-}dom}$" group. The respective control subgroups will be referred to as "$Crl_{(dom)}$" and "$Crl_{(non\text{-}dom)}$" (with indicated between parentheses to which patient subgroup these controls were compared). The upper limbs of the CRPSI

patients are described as “involved” and “non-involved” side and the upper limbs of the controls are described as “dominant” and “non-dominant” side.

*Statistics*
Differences between CRPSI patients and controls for the general mobility outcome measures were tested with the Mann-Whitney *U* test. The Kruskal-Wallis test was used to determine whether there were differences between the four upper limb sides. Differences between the separate upper limbs (involved, non-involved; dominant and non-dominant side) for upper limb usage outcome measures were also tested with the Mann-Whitney *U* test.

## 5.4 Results

*Patient characteristics*
Mean duration of CRPSI since the preceding event was 44.7 months in the $Pnt_{tot}$ group (52.4 months in $Pnt_{dom}$ and 37.0 months in $Pnt_{non\text{-}dom}$ group) (table 5.1). The mean duration of CRPSI since diagnosis was 41.4 months (46.9 months in $Pnt_{dom}$ and 35.8 months in $Pnt_{non\text{-}dom}$ group). No significant rank correlations were found between duration of CRPSI and the upper limb activity outcome measures. All patients showed CRPSI-related signs and symptoms at the moment of measurement, and the majority currently had treatment, either pharmacological or therapeutic.

*General mobility*
There were no significant differences for the general mobility outcome measures between the $Pnt_{tot}$ and the $Pnt_{non\text{-}dom}$ groups and their respective controls (table 5.2). The $Pnt_{dom}$ group was significantly less active (percentages spent in body positions and body motions) compared to their controls ($p=0.028$). Although no significant differences were found for the number of transitions and walking periods, there was a tendency for patients to be less active (especially the $Pnt_{dom}$ group). There was a significant difference in 24-hour mean body activity intensity between the $Pnt_{dom}$ group and their controls ($p=0.047$). There were no significant differences in any of the outcome measures for general mobility between both groups of control subjects ($Crl_{(dom)}$ and $Crl_{(non\text{-}dom)}$ ).

*Table 5.2: Outcome measures for mobility-related activities in ten upper limb CRPSI patients and ten controls. Data are presented as mean (standard deviation) [ranges between brackets] for the $Pnt_{tot}$ group, the $Pnt_{dom}$ group and the $Pnt_{non\text{-}dom}$ group, each with their controls. Because body positions and body motions together comprise the total 24-hour measurement period, p-values with respect to difference between patients and controls are the same.*

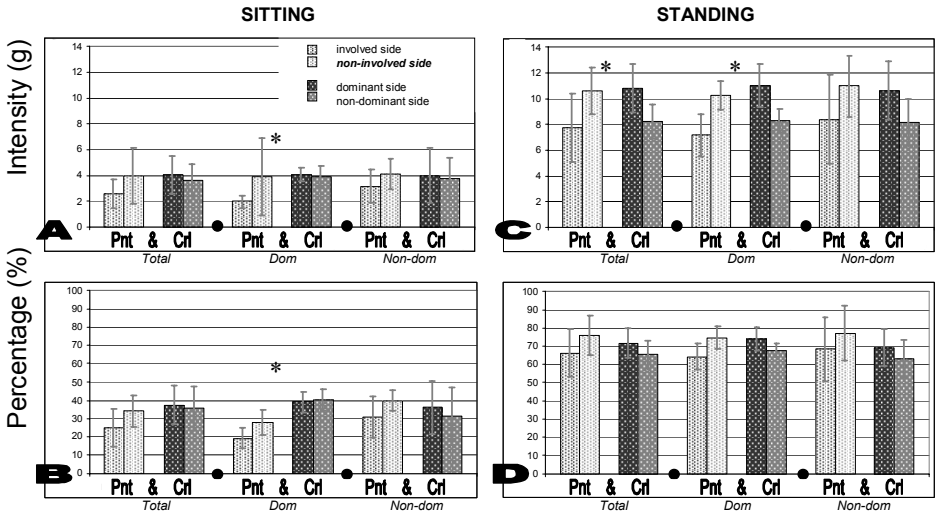
| Outcome measure | $Pnt_{tot}$ (n=10) | $Crl_{tot}$ (n=10) | P-value | $Pnt_{dom}$ (n=5) | $Crl_{(dom)}$ (n=5) | P-value | $Pnt_{non\text{-}dom}$ (n=5) | $Crl_{(non\text{-}dom)}$ (n=5) | P-value |
|---|---|---|---|---|---|---|---|---|---|
| Percentage body positions | 89.2 (5.7) [76.0 - 93.9] | 88.4 (2.3) [84.8 - 91.4] | 0.199 | 92.0 (1.7) [90.2 - 93.8] | 87.3 (2.7) [84.8 - 91.1] | 0.028 * | 86.4 (7.1) [76.0 - 93.9] | 89.5 (1.1) [88.3 - 91.4] | 0.602 |
| Percentage body motions | 10.8 (5.7) [6.1 - 24.0] | 11.6 (2.3) [8.6 - 15.2] | 0.199 | 8.0 (1.7) [6.2 - 9.8] | 12.7 (2.7) [8.9 - 15.2] | 0.028 * | 13.6 (7.1) [6.1 - 24] | 10.5 (1.1) [8.6 - 11.7] | 0.602 |
| Number transitions | 124 (21) [96 - 167] | 146 (53) [80 - 253] | 0.326 | 119 (13) [103 - 137] | 156 (64) [80 - 253] | 0.175 | 129 (28) [96 - 167] | 136 (46) [104 - 216] | 0.917 |
| Number walking periods (> 10 seconds) | 213 (89) [92 - 371] | 221 (54) [131 - 290] | 0.570 | 169 (38) [107 - 199] | 231 (61) [131 - 290] | 0.075 | 255 (109) [92 - 371] | 210 (50) [142 - 275] | 0.347 |
| Body activity intensity (during transport not included) | 2.08 (0.70) [1.41 - 3.32] | 2.41 (0.50) [1.51 - 3.35] | 0.174 | 1.74 (0.28) [1.41 - 2.06] | 2.63 (0.55) [1.80 - 3.35] | 0.047 * | 2.43 (0.86) [1.56 - 3.32] | 2.18 (0.38) [1.51 - 2.40] | 0.347 |

*Upper limb usage*

During sitting, a significant difference between mean activity intensity of the different upper limbs of the $Pnt_{dom}$ group and $Crl_{(dom)}$ subjects was found (p=0.014) (figure 5.3A). Mean activity intensity of the involved limb in the $Pnt_{dom}$ group was significantly less than the other limbs. Overall, the involved limbs of the CRPSI patients were less intensely active than the non-involved limbs and the upper limbs of the controls.

The percentage of upper limb activity of the different upper limbs during sitting was not significantly different for the four sides in the $Pnt_{tot}$ and $Crl_{tot}$ groups, nor for the $Pnt_{non\text{-}dom}$ and $Crl_{(non\text{-}dom)}$ groups. However, there was a significant difference between percentage of upper limb activity of the upper limbs of the $Pnt_{dom}$ group and $Crl_{(dom)}$ subjects (p=0.004) during sitting (figure 5.3B).

*Figure 5.3: Mean activity intensity (expressed in g) and percentage of upper limb activity of the upper limbs of CRPSI patients and controls. From left to right in each graph, results are shown for the Pnt $_{tot}$ group, the Pnt$_{dom}$ group, the Pnt$_{non\text{-}dom}$ group and the limbs of the corresponding controls. Graphs A and B represent upper limb activity during sitting and graphs C and D represent upper limb activity during standing. * Indicates a significant difference between of the four upper limbs.*




During standing, a significant difference between mean activity intensity of the different upper limbs of the Pnt$_{tot}$ group and Ctl$_{tot}$ subjects (p=0.004) was found (figure 5.3C). Also, a significant difference was found between mean activity intensity of the different upper limbs of the Pnt$_{dom}$ group and Ctl$_{(dom)}$ subjects (p=0.004). The percentage of upper limb activity of the different upper limbs during standing showed no significant differences in any of the three groups (figure 5.3D).

Mean intensity and percentage of upper limb activity of the involved side of CRPSI patients were compared with the mean intensity and percentage of activity of the other limbs (i.e. the non-involved, dominant and non-dominant sides). It appeared that the mean intensity and percentage of activity of the involved limb were always less than the mean intensity and percentage of upper limb activity of the other limbs during sitting in the Pnt$_{tot}$ group (table 5.3).

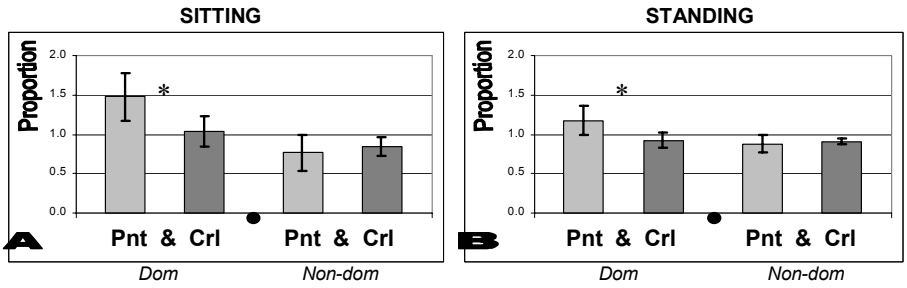
*Table 5.3: Overview of the mean intensity and percentage of upper limb activity: the involved side of the CRPSI patients were compared with the non-involved side of the patients and the dominant and non-dominant sides of the controls using Mann-Whitney U Tests. Each time, it is tested whether the involved limb of the CRPSI patients is significantly less used than the other limbs. Data are presented for the $Pnt_{tot}$ and $Crl_{tot}$ group, the $Pnt_{dom}$ and $Crl_{(dom)}$ group and the $Pnt_{non\text{-}dom}$ and $Crl_{(non\text{-}dom)}$ group, respectively, each for sitting and standing. * $p \leq 0.05$, ** $p \leq 0.01$, $^{ns}$ not significant.*

| | $Pnt_{tot}$ & $Crl_{tot}$ (n=20) | | $Pnt_{dom}$ & $Crl_{(dom)}$ (n=10) | | $Pnt_{non\text{-}dom}$ & $Crl_{(non\text{-}dom)}$ (n=10) | |
|---|---|---|---|---|---|---|
| | Sitting | Standing | Sitting | Standing | Sitting | Standing |
| Intensity Inv < Non-inv | * | * | ns | * | ns | ns |
| Intensity Inv < Dom | * | ** | ** | * | ns | ns |
| Intensity Inv < Non-dom | * | ns | ** | ns | ns | ns |
| Percentage Inv < Non-inv | * | ns | ns | * | ns | ns |
| Percentage Inv < Dom | * | ns | ** | ns | ns | ns |
| Percentage Inv < Non-dom | * | ns | ** | ns | ns | ns |

As stated, the $Pnt_{tot}$ and the $Crl_{tot}$ groups could not be compared with respect to the proportion of upper limb activity because a high ratio indicated more limited in dominant side involvement and a low ratio indicated more limited in non-dominant side involvement. The proportion of upper limb activity during sitting was significantly higher in the $Pnt_{dom}$ than in the $Crl_{(dom)}$ group ($p=0.032$), indicating limitations (figure 5.4A). This proportion during sitting in the $Pnt_{non\text{-}dom}$ was lower than the proportion in the $Crl_{(non\text{-}dom)}$ group, indicating limitations, but this difference was not significant.

Similar results were found with respect to the proportion during standing (figure 5.4B); the ratio was significantly higher in the $Pnt_{dom}$ than in the $Crl_{(dom)}$ group ($p=0.016$). Finally, none of the outcome measures for upper limb usage during sitting and standing differed significantly between both control groups ($Crl_{(dom)}$ and $Crl_{(non\text{-}dom)}$).

*Figure 5.4: The proportion of upper limb activity during sitting (A) and standing (B). For dominant side involvement a high ratio indicated more limitated. For non-dominant side involvement a low ratio indicated more limited. Results are shown for the $Pnt_{dom}$ group, the $Pnt_{non-dom}$ group and their respective controls. * Indicates a significant difference between the proportion of upper limb activity in patients and controls.*




## 5.5 Discussion

*Impact of upper limb CRPSI on everyday life*

With respect to the mobility-related outcome measures, the subjects with dominant side involvement showed significantly lower percentages spent in body motions (higher percentages of body positions) and a decreased mean body activity intensity. But overall, CRPSI in one upper limb did not have a large impact on performance of mobility-related activities during everyday life. The impact on general mobility may be more obvious in patients with acute CRPSI, when signs and symptoms are usually more severe and may more markedly affect activity levels (e.g. afraid to knock the involved limb). In later stages, signs and symptoms may have decreased and strategies may be developed for participation in everyday life (despite remaining signs & symptoms). Finding such compensatory strategies is presumably easier with non-dominant than with dominant side involvement, which may explain the different impact on general mobility in both patient subgroups.

Although the impact of CRPSI on general mobility was modest, there was a clear impact on upper limb activity. The mean intensity and percentage of activity of the involved limb and the proportion of upper limb activity of the patients differed considerably from the controls, and again especially when the dominant side was involved. Upper limb CRPSI had greater impact on upper limb activity during sitting than during standing, which cannot easily be explained, especially because of the small sample size. Inactivity of an involved upper limb could be real disuse, i.e. just not using the limb, or conscious protection (which cannot be distinguished with the ULAM). However, because of the intuitively higher risk of bumping an involved upper limb during standing than during sitting, a patient may be more inclined to protect the

involved limb during standing. This makes it tempting to state that inactivity during sitting was probably more due to disuse and less to protection, which may explain (together with compensatory strategies in chronic CRPSI) why the long-term impact on upper limb activity was more obvious during sitting.

We realize that our findings may be no surprise at all to clinicians and just confirm the supposition of disuse and protection in CRPSI. However, the objectively measured ULAM findings were not in concordance with subjective patient findings (who reported having limitations in both general mobility and upper limb usage). The surplus value of the ULAM is that it enables to study discrepancies between objective and subjective findings, which are more regularly present than one often thinks. Such a study is currently performed in a larger population of CRPSI patients. Objective determination of treatment effect on the activity level may also be performed in future studies.

*Pain behavior and the ULAM*

Pain is most frequently used as outcome measure in CRPSI research [12] and is often described as the most unpleasant feature [2, 5, 16, 19, 20, 22, 42]. However, a problem with pain measurement is its variability during the day, and between patients [22]. Also, acute pain in early stages of CRPSI usually changes to chronic pain at later stages. Acute and chronic pain are different clinical entities [43], which may involve different dimensions [44]. Questionnaires for pain rely on self-reports and are thus subject to biases that may result in inappropriate assumptions and decisions [45]. In a study of the "Pain-Behavior Construct" Turk and colleges [45] considered the idea of Fordyce [46] that there is a vicious circle of pain behavior, because pain behavior is subject to operant conditioning. Pain behavior is observable and consequently measurable [45, 47-49], therefore pain behaviors can be considered an objective way of assessing pain (level). We consider the ULAM outcome measures valid operationalizations of the behavioral dimension of pain behavior as described by Fordyce et al. [50]. However, because the ULAM does not allow measurement of all aspects of pain behavior, the ULAM should be viewed within a broad context of pain evaluation.

*Practical and methodological aspects*

One may wonder whether wearing the ULAM possibly affected what subjects actually did and whether 24-h measurement periods were too short. First, longer periods (up to 72 h) were technically possible and desirable, but it was the first time the ULAM was used in an ambulatory situation and little was known about (dis)comfort of sensors on the (involved) upper limbs. Second, we do not imply that 24-h activity patterns were representative of habitual activities of CRPSI patients. The aim was to get insight into the extent of the impact of CRPSI on general mobility and upper limb usage compared to a group of healthy controls. Third, the subjects were carefully instructed to continue their ordinary everyday physical activities while monitored. Most subjects reported that they had to get used to wearing the device the first few minutes and again when they went to sleep. Nobody considered the ULAM

uncomfortable or too heavy (weight ≈ 500 grams), although two subjects had some aesthetic problems (i.e. 'tourist' look).

Because of an allergy to all normally used fixatives, a special bandage was used for thigh and forearms in one subject and the trunk sensors were attached to her bra (which she kept on for one night), which caused no discomfort and had no effect on data acquisition. Although one patient showed hyperalgesia and allodynia in two fingers, all the subjects could bear sensors attached to their forearms, indicating absence of allodynia or hyperalgesia at sites of sensor attachement. All subjects wore the ULAM for the total 24-h measurement period, there was no non-compliance.

The small sample size prevented us from correlating patient characteristics with the ULAM activity outcome measures, which is currently studied in a larger patient group. Even though statistical power was low, a large number of statistically significant differences were found between patients and controls. Although, the $CrI_{(non\text{-}dom)}$ group was somewhat less active than $CrI_{(dom)}$ group, no significant differences were found, which might have influenced activity levels.

## 5.6 Conclusion

In conclusion, CRPSI in one of the upper limbs does not appear to have a large impact on mobility-related activities in everyday life. However, there is a clear impact on the mean intensity, percentage and proportion of upper limb activity of these upper limb CRPSI patients, especially during sitting. The impact of CRPSI was greater when the dominant side was involved.

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